ADOLESCENT TRANSITION AND TRANSFER TO ADULT HEALTHCARE

Office of Special Healthcare Needs — November 2007

Background

Healthcare Transition, the process of change from child and family-centered healthcare to adult healthcare, is a critical part of the Medical Home concept. The goal of this transition for young adults with special healthcare needs is "to maximize lifelong functioning and potential through the provision of high-quality, developmentally appropriate healthcare services that continue uninterrupted as the individual moves from adolescence to adulthood." [1]

The RI Department of Health's Office of Special Healthcare Needs (OSHCN) conducted a series of pediatric and adult primary care surveys to understand and identify current policies, practices, beliefs, and service delivery gaps related to the transition and transfer of youth with special healthcare needs from pediatric care to adult primary care.

This report focuses on the survey results from the adult primary care physicians. A separate report on the pediatric survey results can be found at www.health.ri.gov/topics/disability.

Methods

During 2006-2007, the OSHCN surveyed all practicing adult primary care physicians in RI on transition and transfer of adolescents to adult healthcare.

A survey questionnaire was mailed to 399 internal medicine physicians and 200 family practice physicians who identify as active primary care physicians in RI*. Of these physicians, 170 internal medicine and 119 family practice physicians completed the survey (the response rates were 43% and 60%, respectively). The 119 family practice physicians included 29 physicians who classify as "continued care" providers, meaning that adults with disabilities in their practice have been their patients prior to adulthood.

The survey included questions addressing the following: physician's policies, practices and beliefs; timing and gaps in transition and transfer; physician's communication with pediatricians; and comfort level, which research has demonstrated is critical to the successful transition and transfer of adolescents into adult primary care.

The results compare responses among the three groups of physicians: internal medicine (n=170), family practice with non-continued care (n=90), and family practice with continued care (n=29). It also compares young adults vs. young adults with special healthcare needs.

**The state's Ob/Gyn physicians were also invited to participate in the survey but the majority of respondents said they did not consider themselves primary care providers.*

[1] American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians-American Society of Internal Medicine. A consensus statement on health care transition of young adults with special health care needs. *Pediatrics* 2002; 110:1304-1306.

Results / Highlights

- The entry of young adults into an adult primary care practice is typically initiated by family members or friends (Fig 1).
- The majority of respondents reported higher levels of comfort in treating young adults with obesity, hypertension, and diabetes in comparison to treating young adults with sickle cell, spina bifida, cystic fibrosis, neuromuscular disease, and young adults who are technology dependent. The family practice physicians who provide continued care reported significantly higher comfort levels in treating young adults with mental health conditions (67%), cardiac conditions (70%), Down syndrome (74%), mental retardation (78%), autism (59%), and paraplegia (70%). The internal medicine physicians reported a significantly higher level of comfort in treating technology dependent young adults (30%) (Fig 2).
- 79% of the respondents reported that young adults with special healthcare needs should be transferred to adult primary care by age 21. 77% reported they never or rarely receive a written transfer summary from the pediatric healthcare provider for their patients with special healthcare needs. 69% reported they never or rarely communicate with the pediatric care providers who previously cared for their patient with special healthcare needs. 94% reported that health plans never or rarely assist with the transfer, and 47% reported that young adults with special healthcare needs in their practice always or sometimes experience gaps in care during the transfer from pediatric to adult care (Fig 3).

Conclusions / Implications

A significant finding of this research is that the majority of adult primary care providers do not feel comfortable in treating young adults with certain medical conditions. It is imperative that adult primary care providers have the necessary skills to serve young adults with special healthcare needs and the knowledge to successfully provide developmentally appropriate healthcare transition services. The OSHCN recommends that key stakeholders from healthcare plans, providers, consumers and relevant organizations collaboratively develop disability competency training for physicians and medical students to ensure young adults with special healthcare needs receive appropriate care and treatment in medical environments.

The results also demonstrate a lack of coordination and communication regarding young adults with special healthcare needs transitioning from child and family-centered care to adult health care. The lack of coordination and communication results in gaps in care and service delivery during the transition process. To address the removal of these gaps, the OSHCN has developed a portable medical summary and provider checklist that can be utilized by physicians to highlight critical medical information that can be forwarded to the adult provider with patient records.

The findings raise concerns that young adults with special healthcare needs are not actively participating in the transition process. To assist young adults in understanding their health needs, the OSHCN has developed a healthcare transition packet, which provides education and strategies on the importance of being involved in this process.

Figure 1

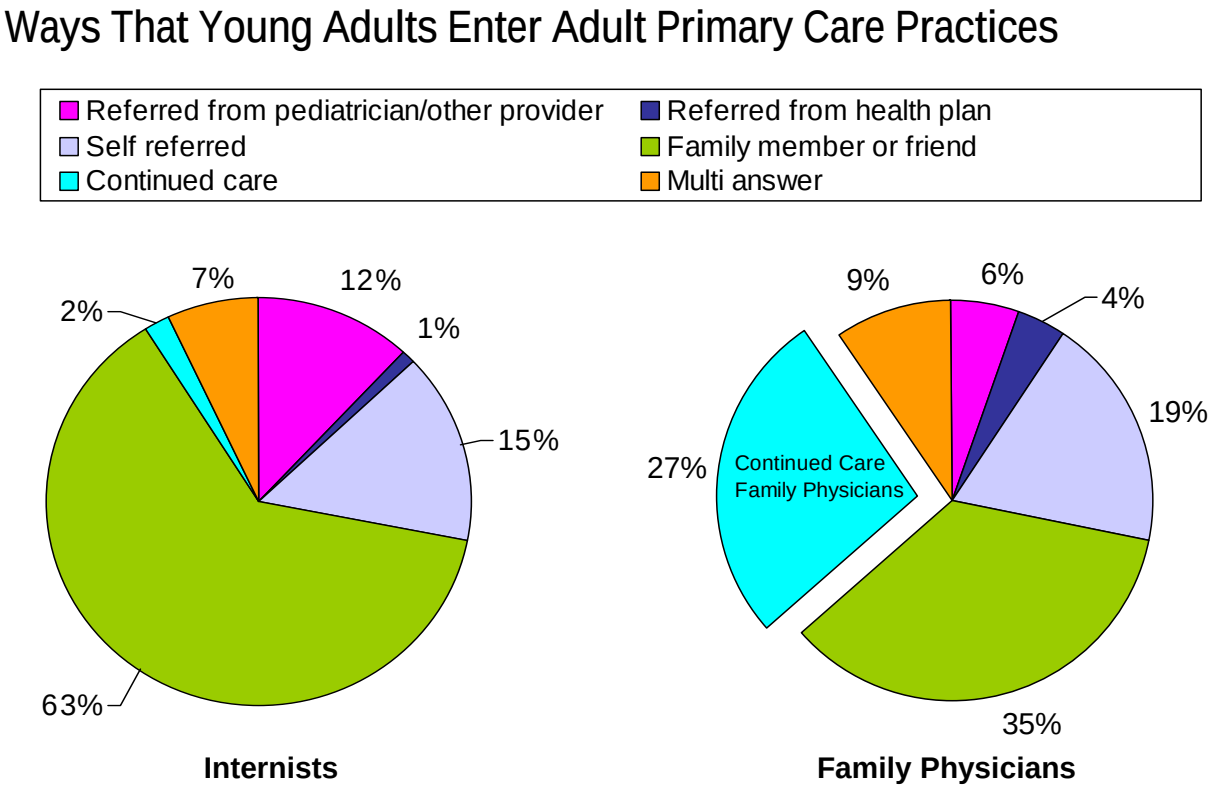


Figure 2

Adult Primary Care Provider Response: Comfortable or Very Comfortable Treating Young Adults with Following Conditions

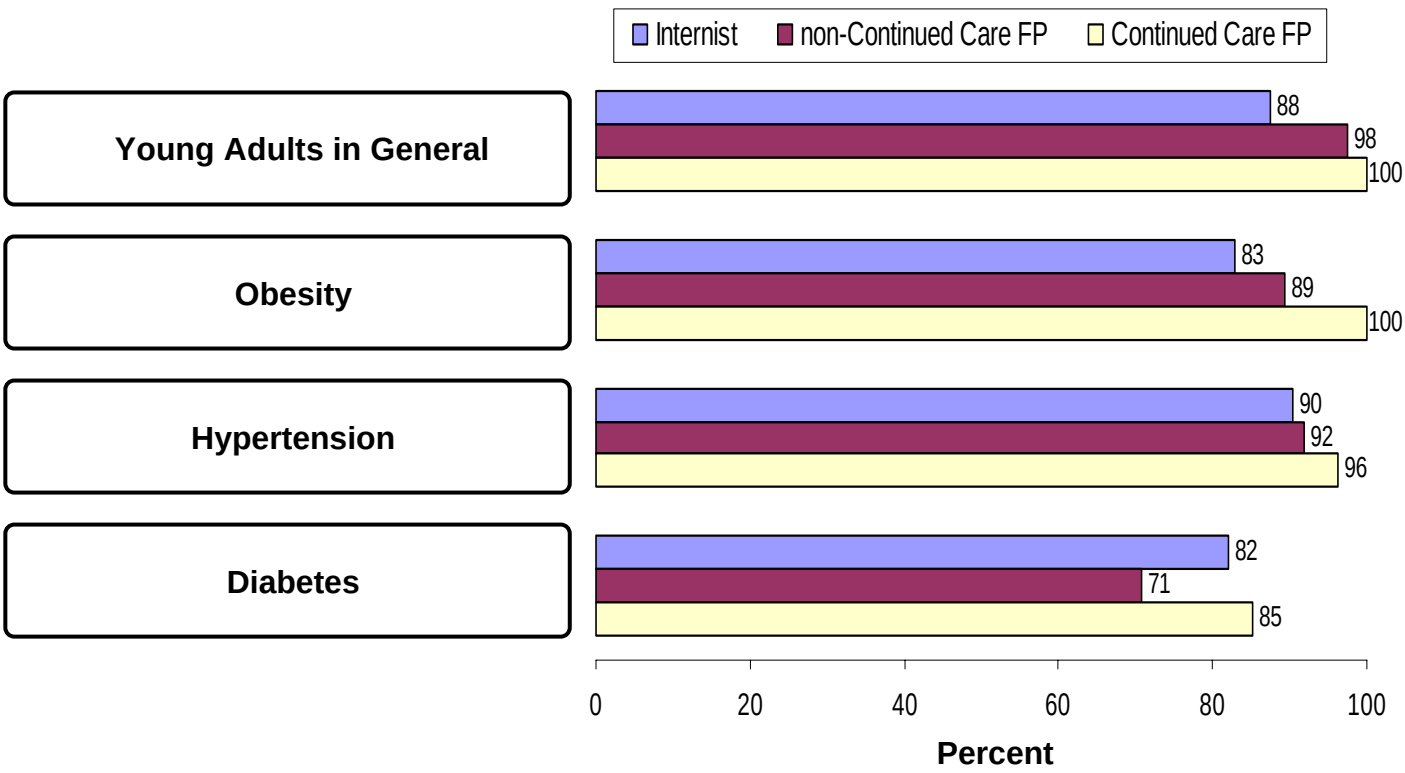
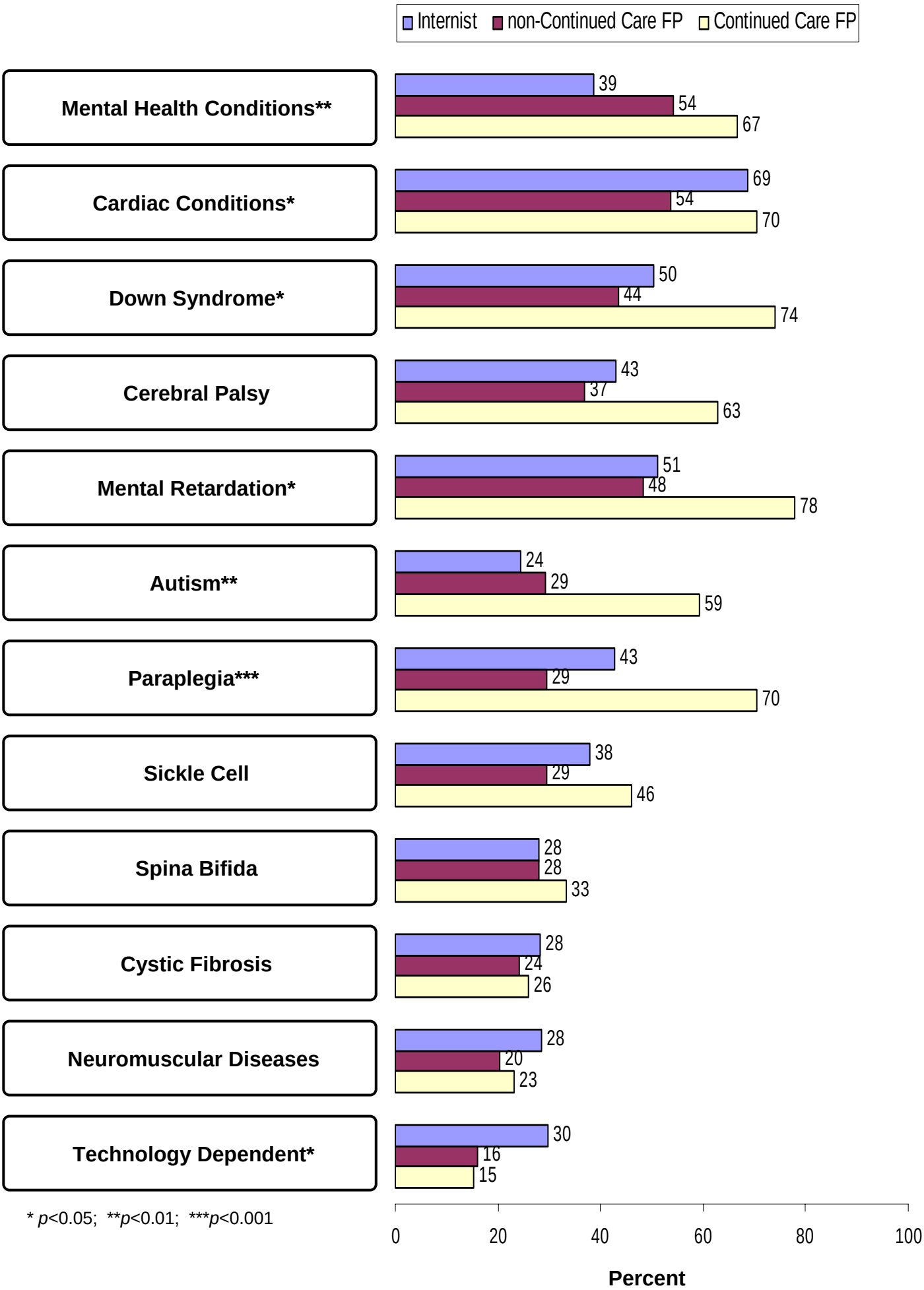


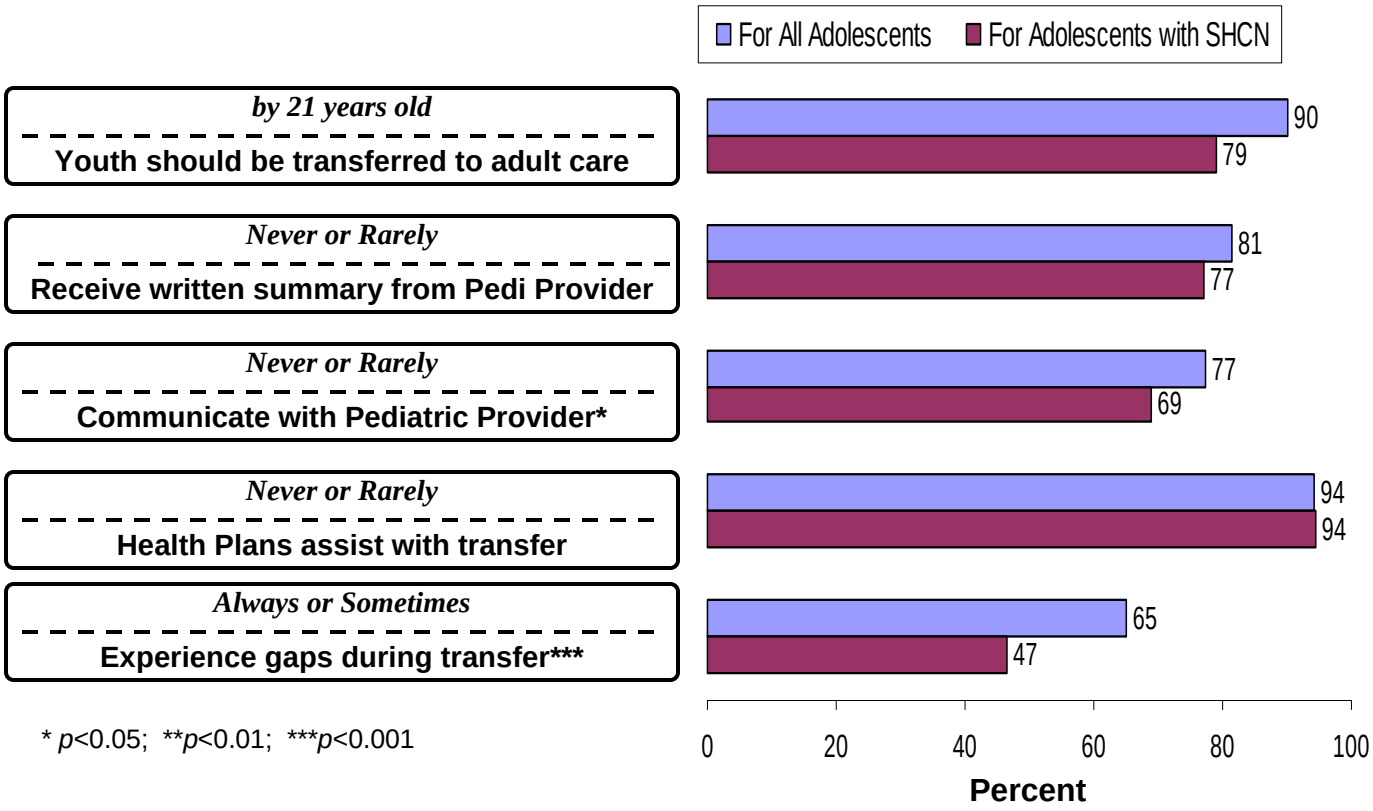
Figure 2 (Continued)



* $p<0.05$; **$p<0.01$; ***$p<0.001$

Figure 3

Current Practices and Beliefs Related to Transition and Transfer Among All Adult Primary Care Physicians (Internists and Family Physicians)



* $p<0.05$; ** $p<0.01$; *** $p<0.001$

Comments

Many respondents shared their thoughts and concerns about the current state of healthcare transition and transfer for youths with special healthcare needs. The following is a sample of these comments:

"One of the major challenges of caring for young adults with disabilities is fragmentation of care. I.e. multiple specialists prescribing. It is very important for all of these professionals to coordinate care which logically should be through the PCP."

"…The lack of continuity makes their healthcare disjointed at times. I feel adults with special needs should have better health insurance than Medicaid "better" meaning more doctors accepting their forms of insurance."

"Probably a state funded seminar each year will help keep all of us updated about services available. Example: -Transportation - Mental Health Care - Home assistance."

"The biggest obstacle is the time it takes in the office, on the phone, filling out forms, talking with other healthcare Providers and social workers etc. about the care of these folks. Time that is not reimbursed that is precious in a busy practice."

"Having the specialist maintain continuity has proven invaluable. One of the biggest problems with this transition is the parents high degree of protectiveness and still considering their young adults as a child."

"Disabled children and teens are almost always insured by Medicaid, which in private practice means charity care. No physician desires to be burdened by this. We accept the occasional patient only out of compassion for them and their parents, but it is no way to run a system. Raise Medicaid reimbursements to commercial rates and there will be no primary care shortage for the disabled."

"Many take too much time - Inefficient and insufficient reimbursement."

"At times I get frustrated by long delays or absence of consult notes and I end up having to rely on parents filling me in re: management plans/medication changes. This works fine with well-adjusted parents, but is very difficult when this isn't the case."

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